

---

## IN Conversation

### Politics From the Inside Out, with Shelley Teed-Wargo

#### Part I

Shelley Teed-Wargo's office has a distinctly tropical ambience. Partly, it's the plants which, against the laws of nature, are always in bloom. (I've checked; they're real.)

Partly, it's the prints on the walls, pictures of sensuous goddesses painted in deep jewel tones.

It certainly isn't the desk, which is strewn with enough paper to suggest not a verdant rain forest, but a depleted one.

Mostly, I think it's Shelley, who doesn't merely think or feel; she burns.

Founder and Executive Director of the Connecticut Union of Disability Action Groups, Shelley is known for her direct, uncompromising take on disability rights issues. She is not known for subtlety, an unfair assessment since her organizing genius is rooted in a highly nuanced appreciation of human capacity and personal dynamics. Shelley gets things done partly out of sheer determination and smarts - is it the Governor's ADA Coordinator who calls her, with wry approval, a "pit bull?" - but that's only half the story.

Shelley gets things done because she is never alone. She moves among her allies and supporters with an intuition acutely attuned to who they are and what they can do. While her personal charisma may get the issues noticed, her successes are always collaborative.

In Part I of our interview, I talk with Shelley about beginnings, transitions and transformations; about family and connections; about hurt and its transcendence. Shelley was unfailingly candid, a fact that will surprise no one who knows her. But candidness can have its costs, which Shelley was willing to risk because she knows that a personal narrative has the power to change lives.

Watch for the second part of this interview in the next issue of the newsletter, when we talk to Shelley about some of her "songs:" her values, her work and the birth of her impassioned politics.

Elanah Sherman

E - What are some of the epiphanies you have experienced in your life?

S - Hmm, epiphanies... epiphanies...

E - Yes, epiphanies... startling moments of insight. Anything, from any part of your life.

S - Actually, this is a story that I tell a lot but I think it really was an epiphany because it was an awakening to the fact that I was different. I don't think before this I truly realized what that meant.

I was in the fourth grade, about 10 years old. I played dodgeball and my classmates and I had figured out the rules of dodgeball for me. The rules had to be a little bit different. If the ball hits my crutches, does it count? Or does it only count if it hits my body? I convinced them that, since my crutches were really just tools that I use, the ball would have to hit my body. At that time, I could move around a lot quicker and easier and my legs were stronger so that when they threw the ball at me I ended up tucking my legs up and the ball would just go under me while I hung on my crutches! So I kept winning the game until my classmates caught on and changed the rules so that if the ball hit my crutches, I was out. That was fine because I figured I had

put it over on them long enough!

This went on for months until one day, a teacher - I call her the Wicked Witch of the West - came onto the playground and looked horrified when she saw me playing dodgeball. She called me over to her... I was basically a good kid, I didn't get in trouble... so being called over by the teacher was, like, uh oh, what did I do? I went over to her and she said, "Look, I don't want you playing dodgeball anymore. It's a liability." It was the first time I heard the word 'liability.'

E - Did you have any idea what this word meant?

S - No, I didn't know what she was talking about, but somehow it sounded like the school would end up in trouble if I got hurt. But it didn't matter if any of the other kids on the



playground got hurt. It was just me who would create a problem if I got hurt. It was very disconcerting to be singled out. Though I had never caused any problem and had just been part of the class, this teacher told me that I can't play dodgeball until I got a note from my mother saying that it was okay. So, I had to go sit on the curb and watch.

I was very upset. I didn't know what I had done wrong or what was so different about me. And I sat on the playground realizing that I was different and that this teacher had pointed it out while it had never occurred to my fellow students that I was different, except that they had to have different rules for Shelley. I sat on the curb thinking about this and it bothered the other students in the fourth grade and they came and joined me on the curb and stopped playing dodgeball.

I found myself in the middle of my first sit-in!

On the one hand, it was a recognition of my difference and that there was something about me that was not allowed. Yet, on the other hand, there was another piece happening at the same time, a support and recognition by my fellow students that I was still who they always thought I was. They didn't understand what happened either.

E - So, even as this experience separated you out, it connected you.

S - Right. After this, I remember my mother really kind of flipping out that night and her writing a note that she let me read before I brought it to school. It said in no uncertain terms that Shelley and only Shelley will decide what she can and cannot do and no one else will decide that for her. When she decides that she will do something, she has my permission to do it.

E - How was disability treated in your family?

S - I have three younger sisters and, to this day, all three of them have said that they didn't really even recognize what disability meant until they were each pregnant and found themselves unable to do certain things like bend over and tie their shoe. It was at that time that they recognized what the inability of doing something was. I can remember times when each of us was expected to do certain chores and my mother would ask one of my sisters, especially my youngest sister, to bring up clothes from the dryer for Shelley to fold. And she would have a little temper tantrum and ask why Shelley can't do that. Not ever recognizing that that was something Shelley could not do and that my mother was just asking her to bring them up so Shelley could do what she could do. It never occurred to my sisters that that was the reason. Even if she told them, they didn't really quite recognize that.

E - Your disability was a non-issue in your family?

S - Pretty much. I think there were times that it came up and it particularly came up during times when I was in the

hospital and my mother was spending time with me, which left my sisters without Mom being around. I think that was really the only time. When I was home, I was just part of the family.

E - Did your status as the oldest child define your place at home?

S - Possibly, but it was also difficult for me because there were times when a young woman without a disability would have gone through certain rites of passage and I was skipped over. The first date . . . my younger sisters all went on dates before I ever had a date. The wearing of pantyhose . . . I couldn't because I was still wearing a long legged brace. The maturing things that a young woman would begin to do, my younger sisters did but I didn't. There were times when I would think, "Yeah, I am different," though to them there was no difference. But there were a lot of small things that pointed out that there was a difference. Through many years, I had to figure out what that meant to me, alone.

E - Were you heavily influenced by your parents?

S - Yes, particularly by my mother. I think I had a very special upbringing which allows me to be who I am. I was taught that I could do what I wanted to do. I was taught that I could be who I wanted to be. It was just up to me to decide what that was going to be. I needed to learn all of the skills that were needed so I could become as independent as possible, to become the person I wanted to be and to take care of myself. And that message took me through life finding where that place was.

But despite the fact that I am where I am because my parents taught me to be independent, my parents also taught me that I needed to be independent because there was not going to be a man who would want to take care of me. I was the oldest of four and I was the only one who was told that I had to go to college. I had to be able to take care of myself. My sisters, on the other hand, were taught that they should learn to do something after high school in case something happened to their husbands.

They were each given hope chests at high school graduation. I made a comment and finally got a hope chest when I graduated from college, but it was one that could also be used as a coffee table.

E: What have you done with these messages? How have you incorporated them into your life?

S - I'm still struggling with that scar - "No man will love you; no man will care for you; no man will. . . You're going to have to take care of yourself."

But my effort, our effort, should be trying to get past that to value yourself and to define yourself despite what people tell you and despite what you hear and despite the hurt you feel.

I was given these limits, I inherited them out of

love and caring. Teaching me independence was a gift, but the other side of the gift. . . Well, I need to come to some kind of balance around this gift and try to determine who I need to be now.

E - Maybe because it's an on-going factor in my own life, I'm always curious about how women make friends with their own bodies. Can you reflect on that?

S - I think I'm still learning that. I think that's part of what I'm kind of looking at more now. I had a meeting here last week and people were laughing and smiling as they went out the door and I had the most excruciating headache. Someone looked at me and asked how I could go through this meeting with such a headache and I told him that I just ignored it. I think this really comes from medical childhood abuse, where I learned to separate body and mind and, years later, I'm getting around to trying to pull the two together.

E - Did you learn to function despite your experience in hospitals by ignoring your body, by pretending that it wasn't an important part of you?

S - My mind would be out of my body, watching what was going on to my body.

E - So now you're becoming reacquainted.

S - Yeah. It feels a little scary, interesting, curious about what that means to me and what that means to others. What does it mean to put the two together? I'm struggling with this now. Until recently, I hadn't thought about my years in the hospital and I hadn't thought about things that were done to me there in my early years as abuse. Maybe I can't fix it, but I can come to terms with it.

E - And coming to terms with this experience means coming to terms with your body in a new way?

S - Hm-mm. Even when I did a sermon for the Unitarians about a year ago I talked about my body as being a vessel and not necessarily who I really am. And I believe that, to a degree. The vessel is what other people see. What I see is who I am spiritually, intellectually, emotionally . . .

E - But not physically . . .

S - The physical I have trouble identifying so much with. It's there - it's not denial. . .

E - It's not denial but it's less than an embrace?

S - It's less than an embrace, yes. It's something that's there and it has to be dealt with. I've had to get past it my whole life to convince other people of who I really am and I ended up skipping over it myself. I meet someone without a disability and I have to convince them of my intellect,

my humor, my charm, all of the things that make up who I am despite what they see sitting in a wheelchair. I've had to help so many people skip over that part to get to the real core of who I am that I end up skipping over that part, too.

E - You're a very passionate person. What do you especially exult in?

S - Gardening, certainly. Just sitting and watching my perennial garden bloom and change with the seasons. Knowing that I started that and it's continued with the help of a higher being, because I don't do a whole lot to it anymore.

Loving my cats, cuddling them and getting such love back. No matter what people say about cats, I never met a cat who didn't really love you no matter what you did, or comfort you. There have been times when I've been sad and lonely and I've been comforted by my animals.

And I love taking walks in the woods.

E - Where else do you find the nurturance that you - that we all - need?

S - My friends, my family. I have a wonderful circle of support and friendship. I have a lot of friends. I have a lot of people who care about me. And they make it known to me. I know that I'm not alone and that there are people I can turn to. A lot of it also is a spiritual part of me that looks to a greater universe to assist me to move on with my life when there are difficulties or to celebrate my life when it's time to celebrate. And I have a connection to the earth.

I was out the other night and kind of absorbing the moon and the stars and the universe as a whole and feeling a great connection to whatever is out there.

E - So let's get to the nitty gritty of this interview . . .

S - Now she wants to know about my sex life . . . !

E - I know that already! I've done my research, I've made the phone calls. All of that will be in the introduction!

Seriously, here's my question. I know you love music and I wonder if there's a piece that you particularly identify with in your life. A theme song, so to speak.

S - This may sound morbid, but I've thought about the music I would want played at my own memorial service. One of the pieces would be "A Simple Song" from Leonard Bernstein's "Mass:" "Sing God a simple song, Sing it loud and sing it long." I identify this piece with the work that I do, which is a celebration of life, of a higher being, of a higher calling.

E - Your work is like a song?

S - Yes, yes, it really is.

## IN Conversation

### "Politics From the Inside Out, Part II"

In our last newsletter, we explored with Shelley Teed-Wargo how her consciousness of self and disability evolved. In Part II, the conversation is more explicitly political, as Shelley and Elanah talk about how Shelley's personal experience became the foundation of a highly democratic and participatory brand of cross-disability politics.

Connection to other people with disabilities came neither early nor easily to Shelley. This is partly because her mother successfully fought for Shelley to receive a totally integrated education. Even when hospitalized and in the company of other children with disabilities over long periods of time, Shelley felt singled out and apart. Her school assignments in the hospital were more sophisticated than the assignments given to most of the other children, probably because her integrated public education was more rigorous than the "special education" offered to others.

Shelley is candid about the extent of disconnection she felt during her childhood: "I went through periods where, I think, I felt I didn't know anyone with a disability who I had anything in common with."

That would change.

E - You were a music major in college and you then taught music for seven years. When did the transition begin into becoming a full-time politico?

S - In 1980, while I was still teaching, I hit the first disability issue that made me mad. It was a handicapped parking issue, which is often *the* issue that starts people on the road to activism. I was parking in a space that was time-limited, but a handicapped parking permit allows you to park at any legal space for an unlimited time. The Hartford Police Department kept giving me tickets. I first met Kathy Coffin [of the Connecticut Coalition of Citizens With Disabilities (CCCD)] when I called her about this issue. She was on the Hartford Commission for People With Disabilities. Kathy suggested some steps and I started calling myself the Shelley Teed-Wargo Fight-Back Committee!

In the process of all this, I was asked to sit on the Hartford Commission.

[Not long after, Shelley left teaching because it had become too exhausting. She enrolled in the Community Organizing program at UConn School of Social Work.]

E - And you began to develop a sense of connection to other people with disabilities?

S - Yes. People like Kathy Coffin and Phyllis Zlotnick [also of CCCD] really influenced me. They had disabilities. And these are simply very intelligent women, these are women who I could admire. They knew what they were doing, they

knew what they wanted to do. I thought that *I* could be like that and that I would *want* to be like that. I wouldn't want to separate myself from these people.

E - Was going to school a transformative experience?

S - Actually, my first day in school may have been another epiphany for me. I was in an elevator, which was supposed to be just a freight elevator. I decided that who I really was was not the person who had been teaching for the last seven years, that I was really someone much different. I had leadership qualities that I had never used. I had pieces of myself that I had buried and I was going to pull them out.

E - Did your political work start after you began at UConn?

S - I was in a line to register for classes and an Organizing teacher came up to me and asked me if I was upset that the library was inaccessible. He asked me if I wanted to do something about it, but I didn't know what to do. He almost literally took me by the hand and took me up to his office and said, "We're going to write a letter." And we began the process of what one does to make a change. We ended up in newspapers and on TV and all this while I'm asking, "Is this really me? Is this really me?" And my Organizing professor would say, "Oh, you need to eat some raw meat!" I'd tell him that I don't eat meat and he'd say, "Then that's what's wrong with you!"

E - When did you begin working for CCCD?

S - Before I graduated. In fact, I was still taking a course from Alta Lasch, who says I never showed up for class anyway! [Alta Lasch is a Director of United Connecticut Action for Neighborhoods and a close CUDAG ally.]

E - It's legendary in Connecticut that you and CCCD were decidedly not a match made in heaven. Where did you go from there?

S - After nine months, I went to United Cerebral Palsy of Northwestern Connecticut as Director of Governmental Affairs. I made a deal with the Director, Thom Briggs, that my job needed to include working with people with disabilities from around the state to put together the kind of organization that *they* wanted. I wanted to see an alternative to an organization that presumed that it was speaking *for* people. I wanted to give *all* people with disabilities their own voice. That became CUDAG.

E - That was in 1988. Since then, CUDAG has received national recognition for being an organization built on the principle of participatory democracy. The CUDAG membership makes the decisions and sets the priorities. The group's legislative successes have been numerous,

including the Personal Assistance Services Waiver.

Now that that's all said and done, I want to make a less than orthodox observation. You often mention women as inspirational figures - your mother, Kathy Coffin, Phyllis Zlotnick. All of your siblings are women, as well. And I've always maintained that CUDAG is a very womanly organization, that it tends to operate on female-identified principles.

S - [Laughter] Well, people like Dale Nielson and Fred Frank [CUDAG leaders] would probably argue with you! Or hope that it really wasn't true or at least that there was *some* male influence in the organization!

E - There may be male influence, but that's something different. CUDAG attends to personal detail in a very female way. The mailings - I've always told you this - couldn't be written by a man, not a heterosexual man, anyway, unless he was under the tutelage of a woman; they're much too inviting. There is a kind of attentiveness that I find totally female. Much like your office.

S - Well, my goddess pictures and my Victorian violet stand *are* rather feminine pieces in the office, I would say!

E - How would you say that your identity as a woman influences your politics?

S - I don't know if it does, but I admit that I *use* my womanness. I use the illusion of my femininity - a small woman who looks sweet and looks like she'd never cause any problems - to temporarily deflect from the fact that when I'm on a mission at the Capitol I'm very able to use a highly masculine way of getting what CUDAG wants. I'm often aware of the trickery I'm using - that when someone really talks to me and feels the assertiveness, it throws them completely.

I'm very much aware of my womanness when I do that, the use of an illusion to create a surprise attack! I have people who hate me for that.

E - Do they feel manipulated?

S - No, I think that I don't fit their stereotype of what a woman with a disability should be, a person who should quietly ask for something and then quietly go away. Now that they've gotten to know me, they know that I don't go away.

E - Beyond the creating of an illusion, how do you feel your womanhood is enacted in your work? [Silence] I have to tell you it surprises me that you have trouble with the question because it seems so obvious to me. This group works differently from how other groups work.

S - It can be one of my bad traits and one of my good traits, but I have a very motherly instinct and I create family around me so that there's a camaraderie, a humor,

a caring, a sensitivity to each other that most likely comes from my being a woman. I know some men who could do that, but I think it is probably easier for a woman to communicate in that way and to make people feel comfortable and part of a special entity, almost another kind of family.

Everyone doesn't stay. Some people leave mad. I don't always know why. Sometimes I think it is because I do what is often seen as a very unwomanly thing, which is to be very direct. I've learned over the years who I can do that kind of thing to.

E - What I see at meetings is that people who attend, no matter who they are or what kind of disability they have, are immediately valued. There is the assumption that anyone who is here has something to contribute.

S - I think that's very much who I am to begin with. And I think it has to do with leadership. I took leadership roles very early in life, but I had some lessons to learn. I remember being president of a youth group when I was in high school. My parents were the adult leaders. During meetings, people would have a great time and I would try to get them to shut up so we could get something done. I'd be screaming and one day my mother, who is not particularly a leader, said to me very quietly, "You might do better and you might have more friends if you spent less time screaming at people."

I began to change my approach to how I brought a group's attention to the task at hand. That's when I began using humor to help people accomplish their goals. Keeping it free and easy enough so that people can still have a good time and a good laugh in the process. This has become one of my major strengths.

New people will call me back after their first meeting and say, "I had a great time at that meeting. Are these meetings always like that?"

E - During your years of organizing, what have you learned from people?

S - I've gotten lots of hate mail . . .

E - No, Shelley, I mean positive things, lessons . . .

S - But this is something that I've learned, that being hated is okay. Early on, it was very hard for me to know there were people who hated me and I've grown out of being concerned with that. I've turned it into something positive.

E - I have to say, that was a truly innovative way of answering my question! In asking you this, I was thinking about myself and the fact that I'm always learning from the people I work with and the people I work for.

S - When you see people come in and they are valued . . . I've had to learn great patience at times and develop other

qualities to allow someone the time or the way they needed to say what they needed to say. I've received from the people I work with such great love that I feel every day that it's a wonderful environment to work in. As one of the members told me the other day, people either love me or hate me. And if they hate me, they're not around me every day, anyway!

E - What do you think there is about you that inspires such strong feeling? And I have to say that even when you talk about yourself you do tend to use extremes in language.

S - Because that's what I feel from the outside. I don't feel that inside. As far as others go, I don't think there's a simple answer. There are a lot of people with disabilities for whom I don't fit their image of disability. Among people with disabilities, there's almost a distrust of other people with disabilities, so when they see me in a leadership position, they don't trust me. But that same thing can also lead some people to want to be like me. These people tend to learn the most in CUDAG.

In any case, I'm the same person who people are either loving or hating, so it's coming out of them. I don't change according to who somebody else is.

E - Let's have a light moment and get existential. How do you conceive the cosmos and your place in it?

S - I'm here to do something very important. And maybe what I'm doing right now is what I'm supposed to be doing. It certainly is for right now. And I see what I'm doing right now as something I will leave behind.

E - You said once that you didn't have the support within your marriage to adopt a child.

S - He wasn't ready and I was coming to a point where it was: We really better do it or I'm going to do something else with my life. So, at some point, probably within the process of starting CUDAG, something else became my goal rather than parenting.

E - Is this how a birth motif has been enacted in your life? Because people are always giving birth whenever they create a purpose for themselves.

S - I wasn't going to leave a child behind, but I'd still leave something lasting after I was no longer on this earth.

E - Last time we talked, I asked you what *you would choose as your theme song*. What's the theme song you'd choose for the disability rights movement?

S - Speaking of my theme song, I was thinking that another one for me would be that Frank Sinatra song, "My Way!"

For the movement? The song from *Les Miserables*, "Do You Hear the People Sing." To me, it's a fight song and a triumph song and a song of struggle and rights and demands. I mean, they were talking about a whole revolution, but, come to think of it, so are we.

Just Published  
And Available Now!

## Help Yourself

### Problem Solving for the Disabled

by Douglas R. Bucy

Macmillan • USA  
\$14.95

Late IN member Doug Bucy wrote this comprehensive book on independent living out of his own experiences.

Among other topics, he covers. . .

- what you may need
- where you can find it
- how you can use the resources you find both inside and outside of yourself to create a productive, satisfying life.

Doug was a pleasure to know and it is our pleasure to recommend his book, which can be ordered at your local bookstore.

Read It!